
Introduction*

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Objectives: This paper introduces the special supplement to the *Journal of the Medical Library Association (JMLA)* that documents the proceedings of the "Symposium on Community-based Health Information Outreach" held on December 2 and 3, 2004, at the National Library of Medicine (NLM). The goal of the symposium was to explore new models of health information outreach that are emerging as technology dramatically changes the abilities of medical and health services libraries to provide resources and services beyond their traditional institutional boundaries, with particular concern for consumer health information outreach through community-based organizations. The symposium's primary objectives were to learn about successful and promising work that had already been done as well as to develop a vision for the future that could inform the NLM's next National Network of Libraries of Medicine (NN/LM) contract. Another objective was to review and assess the NLM's Strategic Plan to Reduce Health Disparities with special emphasis on Native Americans.

Method: The paper describes the background events and rationale that led to the NLM's decision to convene the symposium and summarizes the supplement's ten other papers, some of which were presented at the symposium and some of which were written afterward to capture the symposium's working sessions.

Results: The symposium convened approximately 150 invited participants with a wide variety of perspectives and experience. Sessions were held to present exemplary outreach projects, to review the NLM's Strategic Plan to Reduce Health Disparities, to summarize the research underpinnings for evaluating outreach projects, and to provide a futurist's perspective. A panel of community representatives gave voice to the participants in outreach projects, and sixteen posters describing outreach projects were available, many of them with community representatives on hand to explain the work.

Implications: This *JMLA* supplement provides a comprehensive summary of the state of the art in community-based outreach and a jumping-off point for future outreach efforts.

Advanced information and communication technologies (ICT) are liberating libraries from the constraints of paper, offering opportunities to take on challenges that have heretofore been out of reach. This is especially the case for health sciences libraries. Health professionals, faculty, and students now expect access to health information when and where they need it. In response, ICT allows health sciences libraries not only to meet the expectations of these, their traditional constituencies, but also to offer health information access to constituencies well beyond their traditional facility and institutional boundaries and specifically to the public in their homes and in other places where the public can access the Internet.

These opportunities to offer health information to the public are emerging at a time when health care is increasingly dominating our culture and our economy. At \$1.6 trillion a year, the United States spends more on health care than any other country in the world. While there has been a continuing improvement in the health of the nation generally, the National Center for Health Statistics report *Health, United States, 2004*, observes that "disparities in health and health care exist by race, ethnicity, and socioeconomic status" and that "[s]ocioeconomic and cultural differences among racial and ethnic groups in the United States will likely continue to influence patterns of disease, disability, and health care use in the future" [1]. An important question, then, is how health information outreach can help reduce these disparities.

The extraordinary utilization of the Internet in the pursuit of health information is demonstrable evidence of the importance of health information to the public. The Pew Internet & American Life Project reports that 80% of adult Internet users have searched the Internet for health information [2]. Indeed, enhanced access to health information is creating a new partnership in health care between the empowered patient and the health care provider, yet the obstinate disparities remain, now mirrored in disparities in Internet access [3, 4]. Furthermore, while access to health information on the Internet is transforming relationships in health care, the positive impacts of Internet access are tempered by the challenges of effective utilization of information in this complex environment, as exemplified by a recent report that "only 1 in 6 Internet users say they can consistently distinguish between paid and unpaid results" [5].

Recognizing these challenges, the National Institutes of Health (NIH) developed the NIH Strategic Research Plan to Reduce and Ultimately Eliminate Health Disparities, which "represents a trans-agency commitment to exploring and solving many of the health disparities problems our citizens and our Nation face" [6]. The National Library of Medicine (NLM) has a separate but parallel health disparities plan, the National

Library of Medicine Strategic Plan for Addressing Health Disparities, which is based on the assumption that broadening access to high-quality health information will make a significant contribution to the resolution of the challenges posed by health disparities [7].

NLM provides access to high-quality health information through the National Network of Libraries of Medicine (NN/LM) [8]. NN/LM consists of 8 Regional Medical Libraries (RMLs) and almost 5,500 member and affiliate libraries. The full members are health sciences libraries and health information centers that are regularly staffed, have Internet access and health sciences collections, provide information services, and participate in interlibrary loans. Affiliate members are libraries, information centers, and resource centers that are called upon for health information by their users. The NLM issues a competitive request for proposals (RFP) every 5 years to select the 8 RMLs that coordinate the NN/LM. The RFP for the period May 1, 2006, through April 30, 2011, was released early in the spring of 2005.

In this context, the national "Symposium on Community-based Health Information Outreach" was convened on December 2 and 3, 2004, at the NLM's Lister Hill Center. The symposium had the following goals:

- explore new models of health information outreach that are emerging as technology dramatically changes the abilities of medical and health sciences libraries to provide resources and services beyond their traditional institutional boundaries
- emphasize consumer health information outreach through community-based organizations (CBOs)
- review NLM's Strategic Plan to Reduce Health Disparities with special emphasis on NLM's programs focusing on Native Americans
- inform the statement of work for the next RFP for the RMLs

This special supplement to the *Journal of the Medical Library Association* documents the results of the symposium, which explored the power of collaboration to meet challenges beyond the reach of traditional health sciences library services.

BACKGROUND

The seeds of the symposium were sown in part by the successful Tribal Connections community-based outreach project led by the Pacific Northwest Regional Medical Library (PNRML). With support from the NLM, the Tribal Connections project developed a health information infrastructure serving Native American communities in the Pacific Northwest. While it was not surprising that there were significant challenges in the construction of the technical infrastructure, these challenges seemed easy to manage when compared with the social, cultural, and political challenges involved in extending state-of-the-art information technologies and health information resources into underserved communities [9].

The PNRML's Tribal Connections project proved to

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be a highly successful demonstration project that attracted funding from the Bill & Melinda Gates Foundation to extend the Tribal Connections model to Native American communities in Nevada and in the Four Corners area of Arizona, Colorado, New Mexico, and Utah. The Four Corners area includes the Navajo Nation, the largest-by-population and the largest-by-geography Native American community. Basic infrastructure issues of no electrical power, no water, and no paved roads were common throughout the region, creating special challenges in extending the Tribal Connections model, which also had to overcome barriers related to language and culture. The region is identified by its vibrant Native American communities, but they struggle with desperate economic conditions. The health care challenges include high rates of alcoholism, diabetes, suicide, pulmonary disease, and accidental death [10].

The basic issues of scale necessitated the expansion of the Tribal Connections model to a much more collaborative project involving the four academic health sciences libraries in the Four Corners area and the three RMLs with responsibilities in the area. A meeting was convened in Tucson in June 2003 to discuss the efforts of the PNRML to date, the lessons learned, and the opportunities for collaboration and sustainability. The participants included PNRML staff, representatives from the Resource Libraries in the Four Corners area (the Arizona Health Sciences Library at the University of Arizona, the Denison Memorial Library at the University of Colorado Health Sciences Center, the University of New Mexico Health Sciences Library and Informatics Center, and the Spencer S. Eccles Health Sciences Library at the University of Utah), and the RMLs from the area (the Midcontinental, Pacific Southwest, and South Central RMLs), along with interested NLM staff. The discussions not only illustrated the scale and scope of the extension of the Tribal Connections model but also illuminated a set of larger opportunities for health sciences libraries throughout the country.

The Spring Congress of the American Medical Informatics Association (AMIA) May 28 to 30, 2003, was devoted to "Bridging the Digital Divide: Informatics and Vulnerable Populations" [11]. Experts in medical informatics, health care professionals, policymakers, and others specializing in the provision of health care to underserved populations addressed ways in which informatics can be used to help improve health care access and quality for the underserved and developed a foundation for an action agenda and an informed consensus on key issues of importance. Many NLM and NN/LM staff members attended the meeting and came away with a great interest in exploring how the lessons from informatics research could be married with the practical realities of health information outreach to disadvantaged populations on a large scale.

In addition, the Greater Midwest Regional Medical Library (GMRML) sponsored an invitational Outreach Symposium in Chicago on October 9, 2003 [12]. The GMRML symposium featured speakers who ad-

ressed the health information needs of specialized populations, demonstrated successful outreach projects, and provided strategies for how libraries can partner with CBOs to reach larger segments of target populations. A major component of the symposium was the opportunity for GMRML network librarians to interact with one another in breakout sessions to identify barriers to effective outreach and to share potential strategies for overcoming those barriers.

Finally, the National Center on Minority Health and Health Disparities (NCMHD) was actively supporting evaluations of health disparities plans, and it responded favorably when NLM proposed that it fund an evaluation of NLM's health disparities plan.

In response to the increasing awareness of both the problems and the potential solutions available for addressing the health information needs of the general public as well as of disadvantaged populations, the University of Utah and the New York Academy of Medicine developed a proposal for a national "Symposium on Community-based Health Information Outreach." Both institutions are RMLs, and they represent opposite ends of the spectrum of outreach challenges (rural and urban). Planning for the symposium began in October 2003 with the formation of a symposium planning committee that included representatives from NLM, NN/LM, and experienced community-based health information outreach practitioners (see "Acknowledgments" for a list of the committee members). NLM combined the funds it received from the NCMHD for evaluation of the NLM health disparities plan with funds of its own to support the symposium.

PROGRAM AND PAPERS

The outreach symposium was held over a day and a half (see the symposium Website at <http://www.nlmoutreachsymposium2004.org>). The sessions were Webcast over the Internet, and the Webcast was also archived at NIH:

- Day 1: Thursday, December 2, 2004 <<http://videocast.nih.gov/ram/nlm120204.ram>>

- Day 2: Friday, December 3, 2004 <<http://videocast.nih.gov/ram/nlm120304.ram>>

The Webcast timeline that lists each session is available at <http://medstat.med.utah.edu/symposium/docs/TimeLineCOS.pdf>.

This supplement to the *Journal of the Medical Library Association* is a collection of the papers and panel summaries presented at the symposium, and the order of papers in the supplement follows the order of their presentation: the NLM's Native American portfolio was presented and discussed on the morning of the first day; the afternoon of the first day was devoted to a panel with community representatives; and the morning of the second day gave voice to two panels of researchers and to a futurist. Advance versions of most of the papers were prepared and posted on the symposium's Website, so that participants could review them before attending the symposium.

The first paper in the supplement is "Assessment of the National Library of Medicine's Health Disparities Plan: A Focus on Native American Outreach" by Elliot R. Siegel, Frederick B. Wood, Gale A. Dutcher, Angela Ruffin, Robert A. Logan, and John C. Scott. It addresses the strategies and projects that have been developed by NLM as part of NLM's Strategic Plan to Reduce and Ultimately Eliminate Health Disparities, mentioned earlier. The Native American outreach sector was selected to bring focus to the evaluation and because this outreach sector includes a robust selection of the types of outreach conducted or sponsored by NLM. The paper poses questions about the objectives of the plan, the partners involved to date, the investment of resources, and the outcomes. A companion paper, "The National Library of Medicine's Native American Outreach Portfolio: A Descriptive Overview," provides a detailed inventory of NLM's Native American outreach efforts and tracks the growth in number, breadth, and complexity of the projects in NLM's Native American portfolio. It also provides a large number of examples of community-based outreach as well as a catalog of NLM's efforts in this arena. Together, these papers offer a complete accounting and assessment of the work that NLM has sponsored in this area; they also offer a thoughtful analysis of the strategies that drove the development of the portfolio and what "next steps" should be considered based on the lessons learned to date.

From its earliest planning stages, a key objective of the symposium had been to ensure that representatives from CBOs would be active participants. The symposium planning committee felt that CBOs' participation and perspectives were essential both to validate the program and to educate the health sciences library participants. Therefore, the entire first afternoon of the symposium was devoted to a panel that enabled the CBO representatives to establish a real-world foundation to ground the symposium. The session chairs, Karyn Pomerantz and Roy Sahali, had prepared a set of questions they posed to the panelists. An edited transcript of this session has been prepared by Gale A. Dutcher and Claire Hamasu for this special supplement. Written from the perspective of a librarian seeking the advice of the CBO participants on how to do effective outreach and what pitfalls to avoid, the summary captures the participants' contributions by including selected responses—in the responders' own words—to each of the questions. The themes of building trust, creating a true sense of mutually respectful collaboration, and understanding the environment into which the outreach is being carried out were clearly highlighted.

Assessment and evaluation pose particular challenges in community-based health information outreach initiatives. Yet these activities are essential and are the focus of three papers. Charles P. Friedman's "smallball" essay offers a refreshing perspective on evaluation studies. He suggests that focused evaluations of relatively small sequential steps in a project

are an effective alternative to the overwhelming large-population "powerball" evaluation studies that are carried out in connection with clinical trials. A useful overview of evaluation theory is presented in the paper by Judith M. Ottoson and Lawrence W. Green. They note that the evaluation of community-based outreach is especially complex and that useful results with greater transparency and greater probability of being shared are more likely when participatory strategies are chosen. Cynthia Olney argues that community-based organizations function as complex adaptive systems and that it is essential to have evaluation that helps the project planners understand the complexities throughout a project in order to achieve success.

Gary Kreps, a member of the planning committee who was with the National Cancer Institute (NCI) when the planning began, chaired a panel to explore the perspectives of the research community and to attempt to see over the horizon to identify future opportunities. His own paper examines the challenges posed by the digital divide and presents examples of a broad range of NCI outreach projects that suggest strategies for libraries. Brenda Dervin presents research relating to information seeking and use from the perspectives of two disciplines: communications research, which focuses on developing and disseminating messages to groups, and library/information science, which focuses on meeting the information needs of an individual. Commonalities and contradictions between these two perspectives are presented and illustrated in twenty-five propositions that ultimately lead to libraries more effectively serving the end user. Ruth Parker and Gary L. Kreps provide dramatic examples of how health literacy impacts access to and use of health information and—very clearly—the quality of health care. They point out that solving health literacy problems requires the involvement of health care professionals, other caregivers, family members, and, of course, the patients or consumers themselves.

In the last paper in the symposium, Bern Shen explores the future. Currently, he argues, health sciences libraries have a relatively modest position in "personal health ecologies," noting that fewer than 10 in 1,000 people are admitted to the hospitals in which health sciences libraries are typically located. These 10 people benefit from the information in the libraries indirectly through the health care professionals who are caring for them. However, the economy is increasingly driven by health care, and, as consumers are required to assume more responsibility for health care decisions, Shen draws from the Institute for the Future's work with major companies as they craft their futures to argue that health sciences libraries that extend their services and expertise beyond their traditional constituencies and beyond the boundaries of their institutions—especially to members of underserved communities—can make a significant impact on the lives of the other 990.

OUTCOMES AND CONCLUSION

Throughout the symposium, the associate directors of the eight RMLs collected ideas, concepts, and directions that might inform the next RFP for RML contracts. These were presented in the final session of the symposium. There was a clear consensus that the RMLs should continue to extend the reach of their programs to include partnerships with community-based organizations. The RMLs are well positioned to foster collaborations and to assist NN/LM members in developing the skills that will contribute to the success of these partnerships. Very clearly, the RMLs should continue their efforts to cultivate the assessment and evaluation expertise of NN/LM members. In working with community-based organizations, the RMLs are encouraged to develop multiphased projects that respond to the inherent social and cultural challenges that require a longer-term investment to realize successful outcomes. Interestingly, it was suggested that the RMLs broaden the context of health information to address the complexities of information about such topics as health insurance, as well as the broader challenges of health literacy.

The specific challenges posed to the RMLs lead gracefully to the larger issues and lessons of the symposium. There is little question that partnerships and collaboration are at the core of community-based health information outreach. Librarians clearly have the skills and resources to address the needs of underserved communities, but they often lack the understanding of the complexities and sensitivities of these communities. An absolute requirement is community involvement throughout, and outreach projects require a long-term commitment and strategies for sustainability.

Finally, in addition to the symposium's plenary presentations of panels and papers, sixteen posters that described outreach projects from across the country were on display in two poster sessions (see the poster abstracts on the symposium's Website at www.nlmoutreachsymposium2004.org). It is clear that community-based health information outreach is in that initial development phase when "a thousand flowers bloom." The crucial challenge now is to bring together the lessons of these projects to enhance and sustain future efforts.

In her passionate symposium keynote address, Eugenie Prime, former chair of the NLM Board of Regents, emphasized a need to be receptive to "promiscuous partnerships." She urged NLM and NN/LM "to reach out beyond their traditional constituents" and to choose nontraditional partners that can help in overcoming health disparities at the community level. Prime put health disparities in both human and economic terms and exhorted the symposium participants to embrace the goals of Healthy People 2010:

- increase the quality and years of healthy life
- eliminate health disparities [13]

These goals guide us and measure our success.

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